Autism:
The Public Health Challenge

UW Autism Center

"Dedicated to improving the lives of individuals with autism and their families through intervention, education, professional training, and research aimed at effective treatments, prevention, and cure."

Geraldine Dawson, PhD
November 14, 2005

Autism Impairments: Three Domains

Social interaction

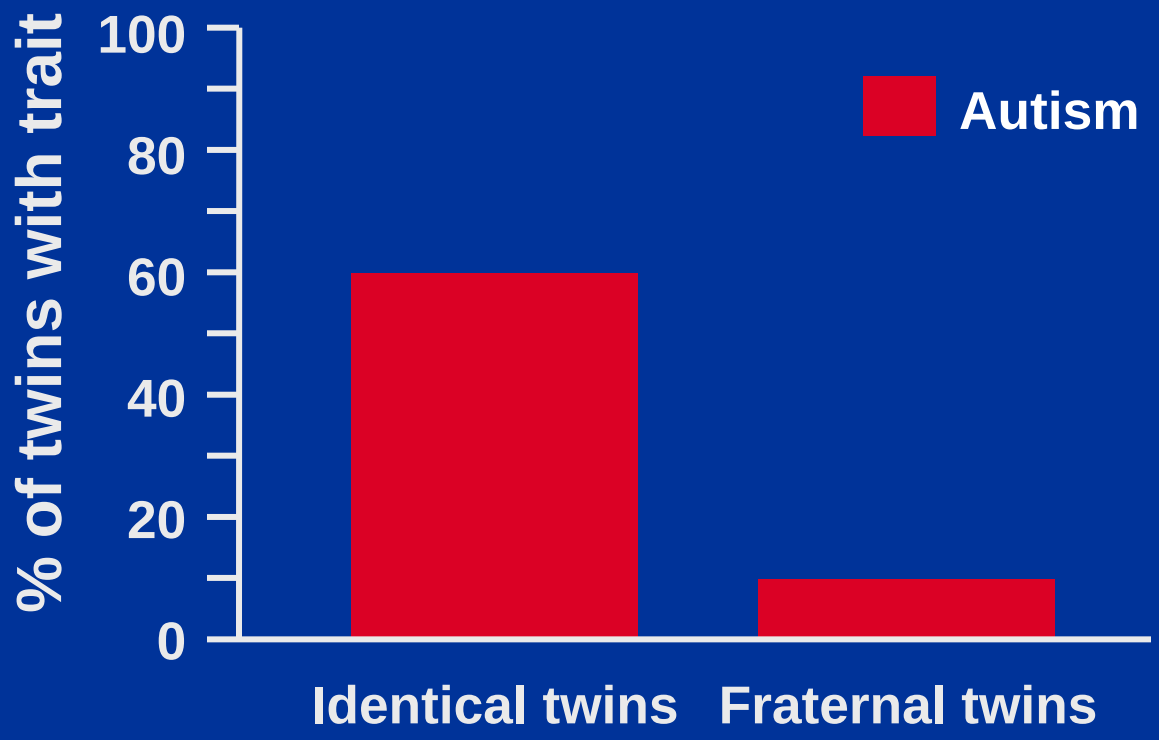
Language and communication

Repetitive behavior and preoccupations

Autism Spectrum Disorders

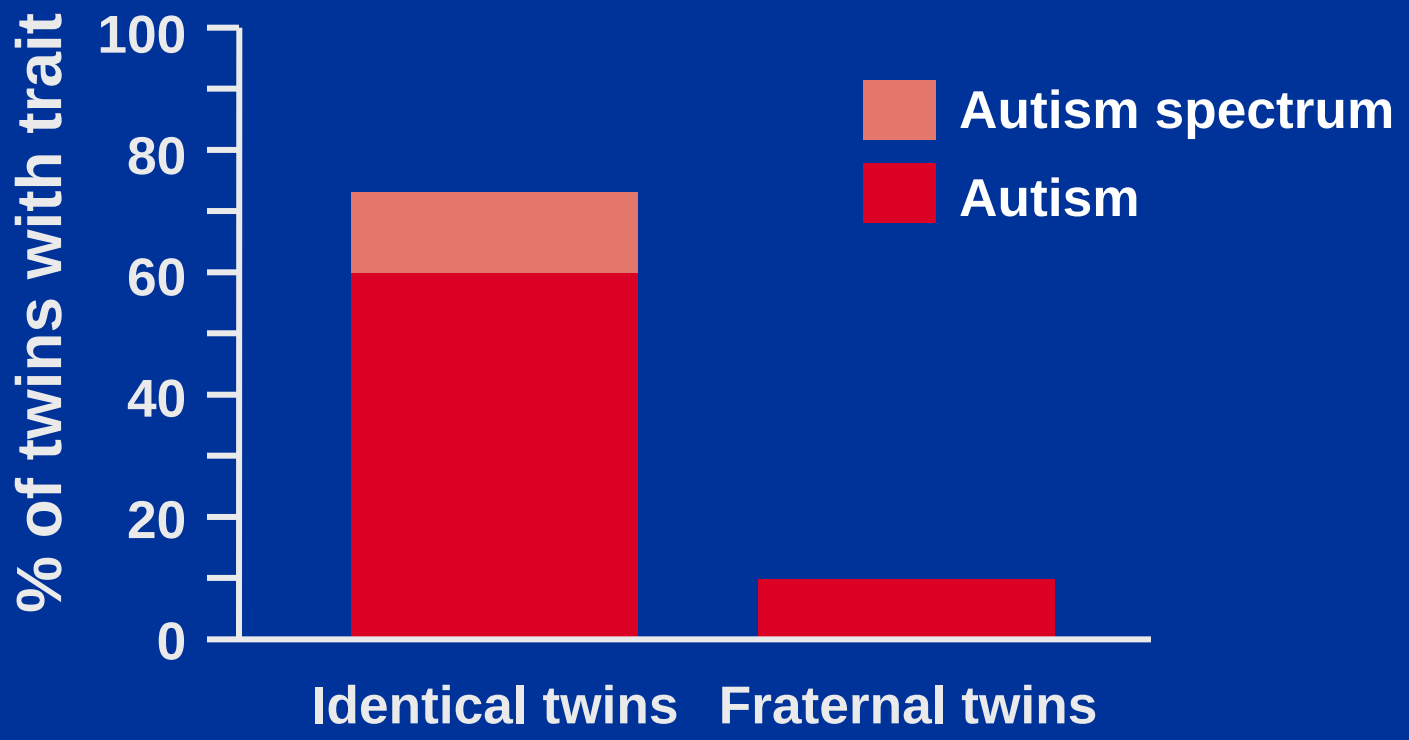
- Wide variability in symptoms and severity
- IQ ranges from superior to severely mentally retarded (25% do not develop speech)
- Male: female ratio is 3-4:1
- Associated conditions include mental retardation, speech delay,, psychiatric co-morbidities, medical conditions, motor involvement
- Treatment should be multi-disciplinary and individualized

Genes play a role in autism



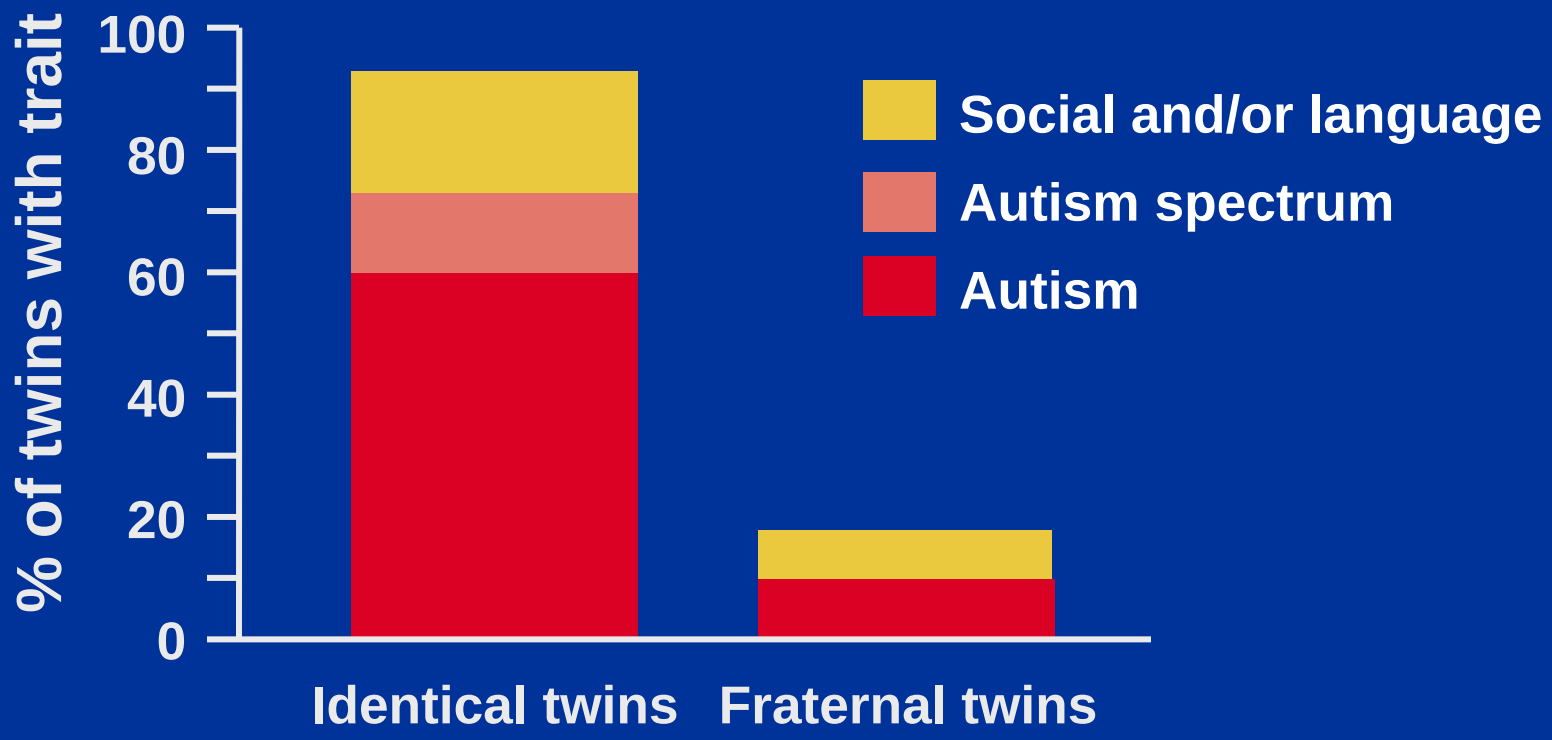
Bailey et al., 1995

Genes play a role in autism



Bailey et al., 1995

Genes play a role in autism

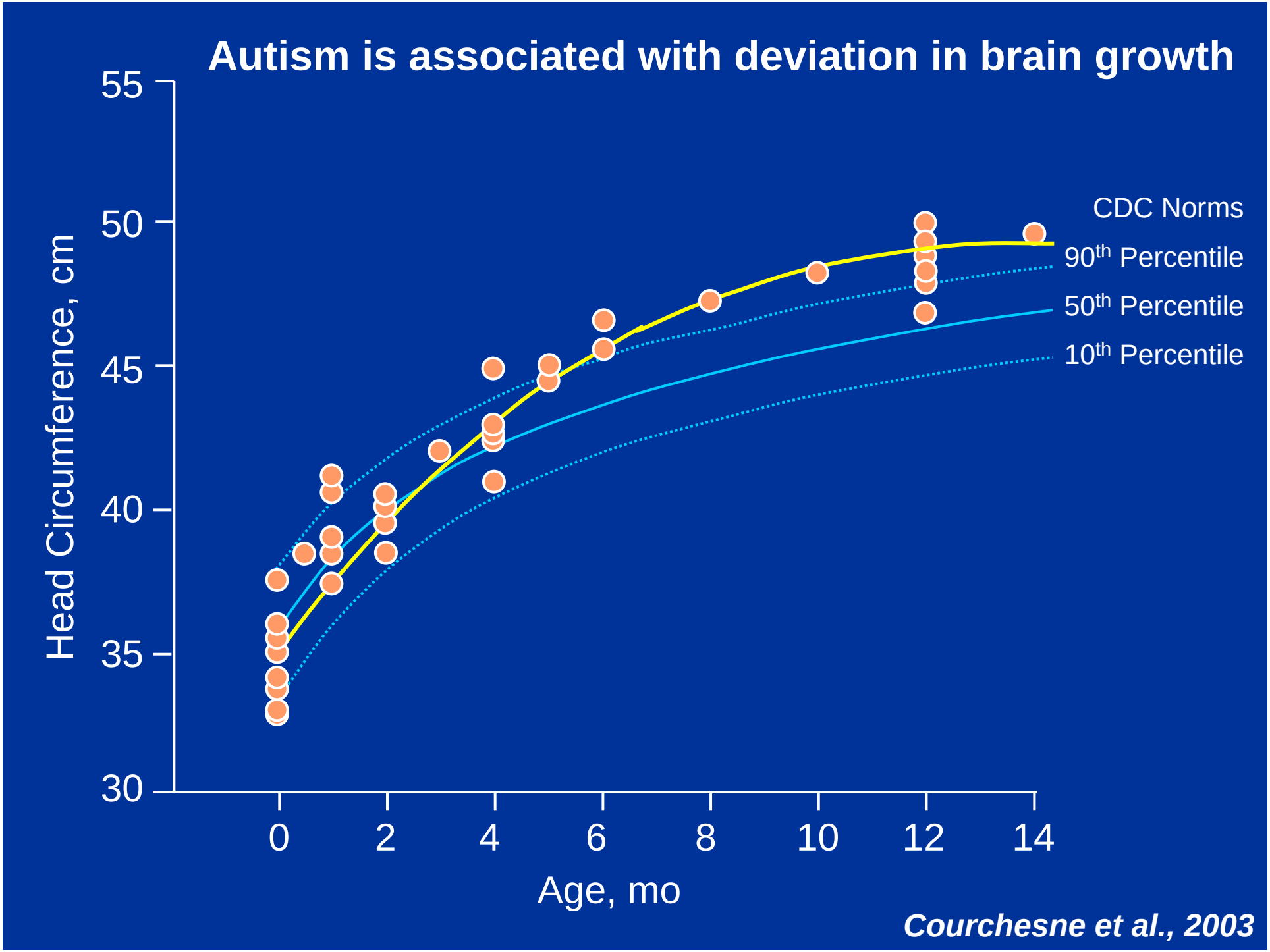


Bailey et al., 1995

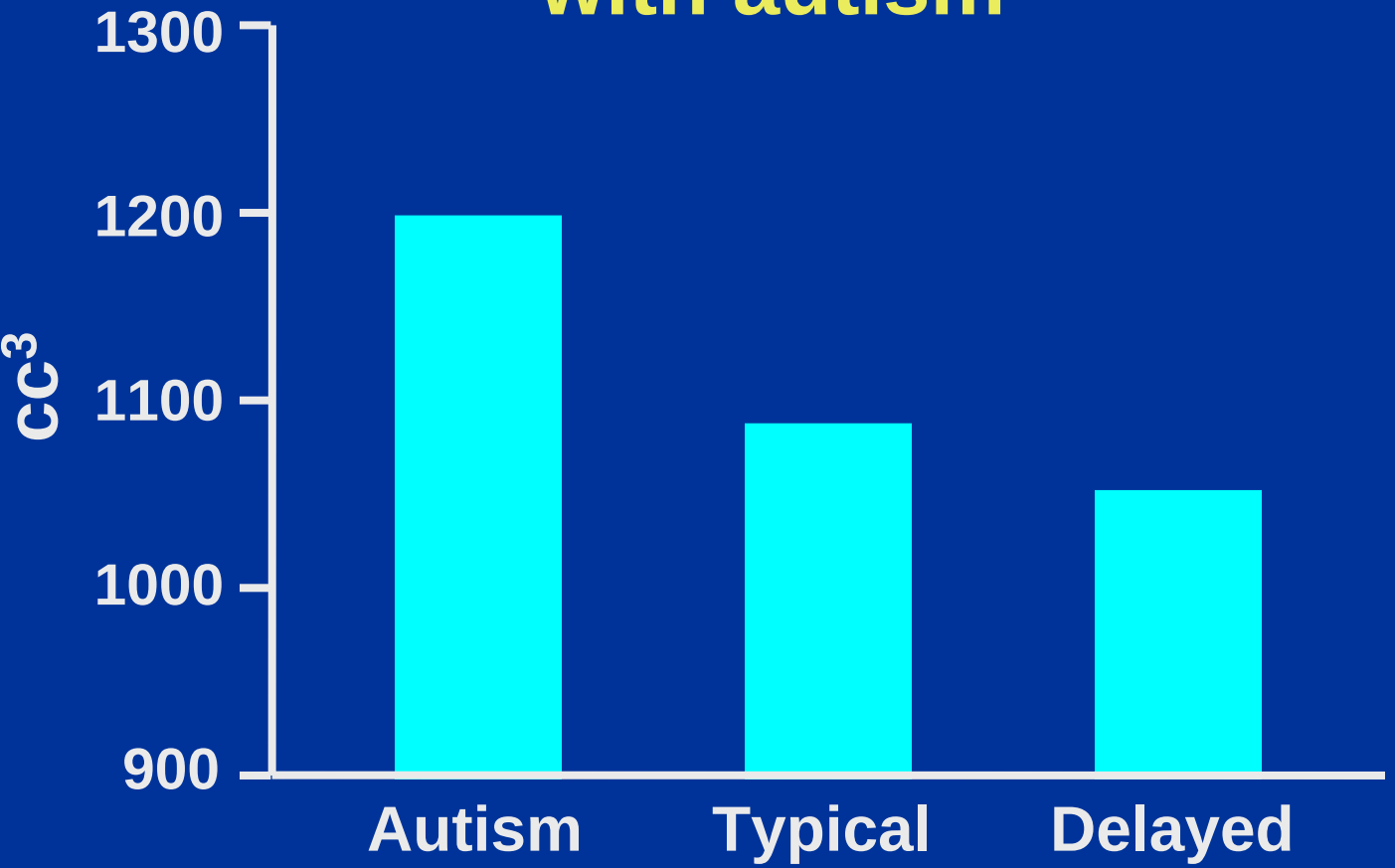
Genes + Environment:

- Viral infection
- Other infections
- Injury (trauma)
- Diet
- Chemical toxins
- Other?

Brain imaging studies indicate early deviation in brain development in autism.


Autism is associated with deviation in brain growth
Head Circumference, cm
55
50
45
40
35
30
0
2
4
6
8
10
12
14
Age, mo
CDC Norms
90th Percentile
50th Percentile
10th Percentile
Courchesne et al., 2003

Brain volume in 3-4 year olds with autism



Sparks et al., 2002

Autism – The Public Health Challenge

U.S. prevalence – ASD: 1 in 166

- Type 1 Diabetes: 1 in 400
- Childhood Cancer: 1 in 2000
- Cystic Fibrosis: 1 in 3500

Estimate of ASD children <18: 450,000 in U.S.
Total estimate ASD: 500,000 – 1,000,000

Adapted from Insel, T., Director, NIMH, 2005

Measuring the Public Health Challenge

World Health Organization "Burden of Disease"

- **Prevalence**
- **Functional impairment**
- **Chronicity**
- **Age of Onset**
- **Cost**

} "Disability Adjusted Life Year"

Autism > Type 1 Diabetes, Childhood leukemia, CF

Adapted from Insel, T., Director, NIMH, 2005

Autism – The Public Health Challenge

- Costs – ASA estimates $90B/yr; 90% adult services
- IDEA - autism from 20,000 in 1993 to 120,000 in 2002
- Cost/pupil average $18,800 (3x non-special educ.)
- Attributable IDEA costs for autism: $1.4B/year

Adapted from Insel, T., Director, NIMH, 2005

Meeting the challenge in Washington State: A three fold strategy

- ✓ ***Improved early detection and access to early intervention***
- ✓ ***Access to life long, multi-disciplinary services***
- ✓ ***Professional training to build capacity for services in community***

✓Early Detection

Autism can be detected by 18 months in most cases

However, the average age of diagnosis is much later!

What is the average age when children are diagnosed with autism?

Philadelphia County, Medicaid Data - 1999

	White (n =118)	African-Am (n = 242)	Latino (n = 33)	Total (n = 406)
Age Diagnosed	**6.3 (2.9)**	**7.9 (3.1)**	**7.4 (3.5)**	**7.4 (3.1)**
Number of visit until diagnosed	**4.1 (19.0)**	**13 (39.8)**	**8.3 (18.6)**	**9.6 (33.0)**

Significant disparities based on race and ethnicity : African American children diagnosed 1.5 years later and require 3x # of visits

Mandell et al., JAACAP, 2002

Early screening tools

- The Checklist for Autism in Toddlers (M - CHAT) can be used to identify autism at 18 months
- M-CHAT found to have sensitivity of 97% and specificity of 95%

✓*Early intervention*

What we know:
Long term prognosis is poor without substantial intervention

- Many remain mute their entire lives
- 75% are mentally-retarded and need life long intensive care
- 41% require psychiatric hospitalization
- Very few develop meaningful friendships or marry

What we know:
Early intervention makes a difference

- Early intensive intervention is very effective for some children

- A substantial proportion of children are able to attend regular education classes

- Average IQ gain of 1.5 – 2 SDs

- Children with higher IQs (>35) are likely to respond better

- Gains may be stable into adolescence, especially with ongoing assistance

What we know:
Early intervention is cost-effective

Cost-benefit analyses of early intervention

Jacobson et al. (1998)	~ $200,000 per child 3- 22 years ~ $1,000,000 per child 3-55 years
Columbia Pacific Consulting (1999)	~ $1,000,000 per child 3-55 years

Available services lag behind scientific knowledge: Impact on families

- Parents often left to fend for themselves
- Endure great emotional and financial hardship
- Accessibility, affordability, and feasibility pose barriers
- Partially/totally withdraw from workforce
- Marital distress
- Depression

Common elements of effective programs

1. Comprehensive curriculum addressing core domains of imitation, language, toy play, and social interaction

2. Sensitivity to normal developmental sequences

3. Highly supportive teaching strategies based on applied behavioral analytic procedures

Common elements of effective programs

4. Behavioral strategies for reducing interfering behaviors

5. Involvement of parents as partners

6. Gradual/careful transition from highly-supportive environment (usually 1 to 1) to less structured environment (small group)

Common elements of effective programs

7. Highly-trained staff

8. Supervisory and review mechanisms

9. Intensive, i.e., ≥25 hours per week of structured intervention for at least 2 years (per National Research Council recommendations)

10. Onset of intervention by 2 years

✓Access to life-long multi-disciplinary services

- Transitions (e.g., early intervention program to elementary school) are especially vulnerable periods
- Proactive approach prevents serious problems
- Avoids costly care (full time aide, psychiatric hospitalization)
- Offers hope for productive, satisfying life for all individuals

Treatment should be individualized and multi-disciplinary

Medical needs

- **Metabolic/genetic conditions (10-20%)**
- **Seizures (25%)**
- **Sleep disorders**
- **GI problems**
- **Allergies**
- **Co-morbid psychiatric conditions**

Psychosocial needs (e.g., social skills)

Educational needs

Speech and language services

Occupational therapy

Comprehensive Care Model

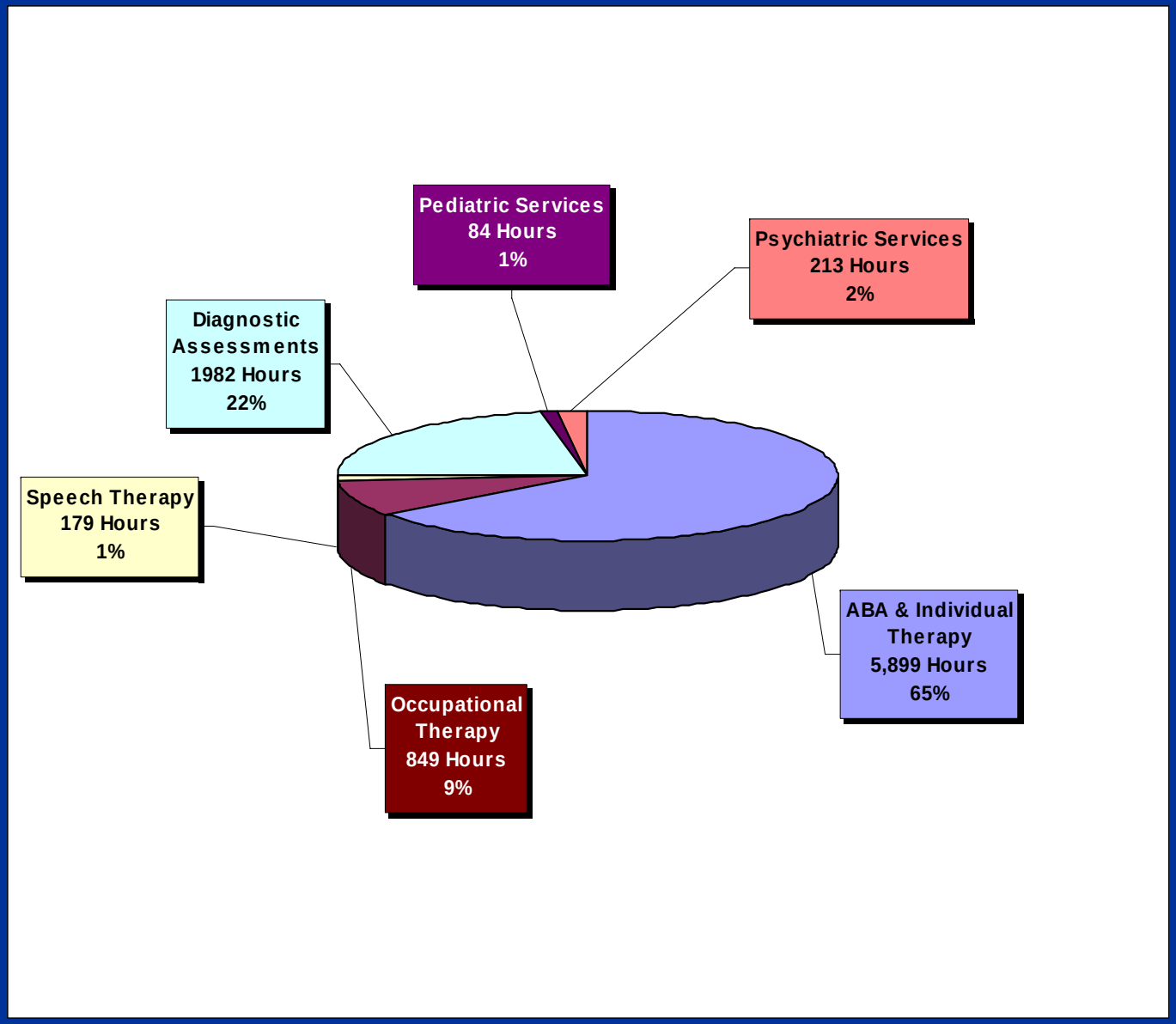
Multi-disciplinary care:

- **Psychologists**
- **Educators**
- **Applied behavior analysts**
- **Speech/language pathologists**
- **Occupational therapists**
- **Medical professionals**

On-going services needed by school age – adolescent children

- Educational program sensitive to needs of child with ASD
- Physician-related services
  - Medical conditions (e.g., seizures)
  - Pharmacological treatment (e.g. anxiety)
- Social/vocational skills training
- Periodic assessment/counseling
  - Psychoeducational assessment
  - Behavioral challenges
  - Emotional issues

Types of services provided at UW Autism Center



Services provided by UW Autism Center
July, 2004 – June 2005

- >600 families served by Center staff
- 9,206 hours of clinical service
- 5,899 hours of behavioral intervention provided to families
- Many families still on wait list
- Satellite clinic in Tacoma established to address growing need for services

UW Tacoma Satellite

UW Tacoma

- Funded as part of UW budget by State Legislature
- Spearheaded by Senator Marilyn Rasmussen
- Primary goals: Clinical services, training, outreach in South Puget Sound area

✓Professional Training

“Give a man a fish and he will eat for a day. Teach him how to fish and he will eat for a lifetime."

Chinese Proverb

Building capacity through training

Autism Center trainees

- *Neurology and pediatric resident training*
- *Postdoctoral clinical psychology fellowships*
- *Occupational therapy student training*
- *Psychology graduate student practicum*
- *Early intervention therapists (UW students)*

Community training

- *Summer intensive program*
- *School professionals practicum*
- *Educational programs at middle and high school level*
- *Workshops and in-service training*
- *UW service learning courses*

Teen Mentoring Program

Fellowship awarded to develop service learning course for UW undergraduates

UW undergraduates serve as mentors

Help teenagers with autism acquire and practice social skills

Teens with ASD mentor younger students

Partnership is the key

Families

Government

Professionals

Adapted from Insel, T., Director, NIMH, 2005

Summary

The need is great.

The opportunity for change is great.

If we don’t do it, who will?

Adapted from Insel, T., Director, NIMH, 2005